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Supplementary information:

Panel 1: Focus group 1: Men on AS

Consistent clinical team, administration and follow-up protocol

Participant	Age	Months on AS	Quote
1	65	29	“my nurse specialist always sees me for my psa review, I have a great relationship with her, I could ask her anything. I trust that she is following the follow-up protocol as she is able to put my results into context and we discuss what will happen at the next visit every time I come”.
2	71	43	“ I found the leaflet on active surveillance really important. I needed to understand how often I would be seen and what I could expect in terms of tests. I’m really happy as I usually see the same 2 or 3 doctors or nurse – it adds to a feeling of consistency.
3	64	28	“being in a dedicated active surveillance clinic – I’m not? Oh, I thought I was, I always see the same person”.
4	70	54	“An explanation of the next steps of follow-up every time I go to clinic is really important - reassuring”.
5	66	43	“I have had a couple of appointments moved but this is understandable over a 4 year period”.
6	58	40	“when my appointments are moved I can always contact my nurse specialist, he’s always very helpful and has sometimes given me my results over the phone to save me a trip to hospital”.
7	69	33	“access to my nurse specialist is most important to me”
8	51	31	“always being able to leave a message and someone getting back to me”.
8	51	31	“I can often get my results over the phone which is much more convenient”.

6	58	40	“There are some questions I need to ask a doctor. Some reassurances are needed from a doctor but some things I need to speak to my nurse about”.
3	64	28	“’I get more time from my CNS, most of the time I just need encouragement to stay with the programme – that’ what my CNS does”.
5	66	43	“My nurse is great, she checks up on me. I wouldn’t have committed to my new diet and exercise plan if she hadn’t. It felt like she was invested in me, that what I was doing was really helping me control my cancer”.
8	51	31	“my CNS always sees me for my PSA review, I have a great relationship with her, I could ask her anything. I trust that she is following the follow-up protocol as she is able to put my results into context and we discuss what will happen at the next visit every time I come”.
6	58	40	“I found the leaflet on active surveillance really important. I needed to understand how often I would be seen and what I could expect in terms of tests. I’m really happy as I usually see the same 2 or 3 doctors or nurse – it adds to a feeling of consistency.”

Panel 2: Focus Group 2: Men who had opted out of AS

Consistent clinical team, administration and follow-up protocol

Participant	Age	Months on AS	Quote
9	69	12	'The doctor didn't even let me sit down, he greeted me at the door and said your PSA is fine, see you next year. I had questions, I wasn't encouraged to ask them'…..'after leaving the clinic I couldn't even remember what my psa level was, I had to call the nurse later that same day. 'I was told all I needed to know was that I didn't need to worry myself – that was it, end of conversation'.
10	66	19	'I saw another new doctor. She kept looking a piece of paper that she explained was the follow-up protocol. She changed her mind 3 times before I had the correct information. I might have missed an important scan if I hadn't asked additional questions. My confidence was gone, I was upset. She apologised and said it was her first week with a new team. Not being funny, but that wasn't my problem'
11	64	24	'I'd never met the oncologist before. I just felt like they were changing the goal posts, I was comfortable with the urology team seeing me every 6 months then the oncologist suggested 3 monthly blood tests. There was just no consistent plan'
12	55	12	"I don't think people appreciate that when your appointment is approaching you feel anxious and stressed. When they cancelled my appointments I started to question just how safe it really was. I couldn't cope with that". And, "My nurse didn't think changing my appointments was a big deal, she just kept saying that I was one of the lucky ones and that I didn't need to worry – easier said than done!".

13	63	18	“I work away - there should be a direct line to the admin team, I always went round the houses when I needed to change an appointment”
14	59	18	“appointments shouldn’t be cancelled unless you speak to the patient. I got several letters in the post and worried myself sick whenever an appointment was brought forward. I thought it was because of my cancer, I didn’t realize it was because of someone’s’ holiday. At the very least this should be explained at the beginning”.
15	70	12	“I never felt like I was seeing a specialist in AS. I just wanted someone to be interested in AS”.
11	64	24	“nobody could give me any guarantees about AS follow-up, every guideline seemed to be different. It made me very nervous”.
14	59	18	“very difficult. I didn’t feel that I had a relationship with anyone as I didn’t see the same person more than twice” and…. “when I saw someone new, which was every other time I came to clinic, it was like starting again”.

Panel 3: Focus Group 1: Men on AS

Detailed and consistent information

Participant	Age	Months on AS	Quote
6	58	40	**"**I know that a friend of mine went to a class before he had his prostate out, they should do that for men on AS"
7	69	33	"The PCUK website is updated all the time, it was a great recommendation for information"
1	65	29	"I like asking questions when I see my team. I think that's the only way you keep up to date"
7	69	33	"I go to the support group once a month, it means I can speak to a nurse every month if I need to"
5	66	43	"I go to the support group as well, I think the expert education sessions that they run are brilliant".
3	64	28	"I was given some information leaflets by my CNS. I thought they were very good"
4	70	54	"I asked lots of questions about PC when I was first diagnosed, I trusted that the doctor was giving me the right information. I was given some leaflets which I think I read, but I haven't re-read them since. I think it's more important to ask questions at each appointment".

Panel 4: Focus Group 2: Men who had opted out of AS

Detailed and consistent information

Participant	Age	Months on AS	Quote
9	69	12	"You can't just tell someone not to worry about 'Cancer". If I had better understood how slowly my cancer was growing I might have stayed on AS. The doctor used words like you "could" stay on AS and its "possible" you won't need treatment. Believe me, when you've got cancer you need more reassurance!"
10	66	19	"I asked for some websites that I could look at.. When I had looked through them I drifted onto others that were frightening. I spoke to my CNS who just kept telling me not to worry. It would have been nice to have sat down with the doctor to answer some time of the questions I had. I got the sense that my cancer was insignificant and therefore so was I"
12	55	12	"every time I saw a new doctor or nurse I would question them about PC and AS. Sometimes the answers were the same, other times they sounded like they didn't know what they were talking about. They weren't able to answer questions about my situation in relation to the average AS patients. It didn't fill me with confidence"
14	59	18	"the only time the doctor seemed keen to discuss my cancer was when I said I wasn't happy to continue AS. I spent an hour with him then but up until that point appointments had been rushed - I felt like I was annoying them for asking too many questions".
12	55	12	"It's difficult to be told you've got cancer at 49 and told you don't need treatment but someone would see me every 3 months. If they had to check on my

			that frequently that didn't seem very safe to me. I wasn't offered any context"
15	70	12	"I think there should be a dedicated clinic for men on AS. Every time I saw a new doctor they changed the follow-up – why couldn't we have a copy of the AS follow-up guideline".
14	59	18	"I opted out of AS as I didn't feel like I was getting a straight answer. I kept asking when would I know that I needed treatment and I got a different answer each time'…'I now know that it's different for everyone depending on prostate size and grade and number or biopsy cores, but nobody explained that at the time"
11	64	24	"I was given some information on AS, I think it was 2 pages long, I spoke to my friend who had also been told he had PC, he was given 4 booklets, when I asked my nurse why that was she said I was lucky, that I didn't need to worry about my type of cancer – I didn't know what this meant, but she didn't offer any more information"
14	59	18	"I'd had very little information or support whilst I was on AS. When I decided I would have surgery suddenly I was attending a seminar, was encouraged to attend the support group and was in regular contact with my nurse – for the first time I felt in control of my cancer, and most importantly not alone".

Panel 5: Focus Group 1: Men on AS

Diet and lifestyle advice

Participant	Age	Months on AS	Quote
7	69	33	"I changed my diet and started to swim twice a week, and finally felt as if I was doing something positive, something that would help me"
4	70	54	"The most useful conversation I had with my doctor and nurse was about diet and lifestyle changes, I know there wasn't much evidence for it but it's made a huge difference to me. I've lost 3 stone and I've been able to stop my blood pressure tablets. It sounds strange but this cancer has given me back my life, I'm fit and healthy and able to keep up with the grandkids!"
2	71	43	"I've joined a cancer and complimentary therapies group on the PCUK forum, it's really helped with advice"
3	64	28	"My doctor didn't know anything about diet or exercise, he suggested I speak to my specialist nurse – she didn't know anything useful either. Everything I did was researched on the internet. I don't know if it was all correct but at least I felt like I was involved and taking charge of my cancer!"
8	51	31	"I had a really good chat with my doctor when first diagnosed, I was really pleased that he seemed to know how important it was to feel that I was doing something proactive"
4	70	54	"My nurse had lots of advice on where to go for free exercise classes. I've joined a walking group and a local gym".
6	58	40	"I found lots of information on the internet about diet and exercise. I changed my diet and began to go to the gym. I think everyone who has cancer should be

			aware. It's kept my mind and body busy, I've never felt better"
8	51	31	"my nurse specialist didn't seem to know much about these things but suggested a great website so that I could investigate myself. I've now been on a couple of courses – it's really been empowering".
2	71	43	"I must have had the same CNS. Mine suggested a website too and I've been on a couple of courses in Bristol – it's been a really positive experience".

Panel 6: Focus Group 2: Men who had opted out of AS

Diet and lifestyle advice

Participant	Age	Months on AS	Quote
14	59	18	“there really wasn’t any information on how I might help myself on AS” and “I don’t think the nurses or doctors believed that diet, exercise or complimentary treatments would help on AS. I had done lots of reading and I couldn’t engage them in this so I gave up. I might have stayed on AS if I’d had the opportunity to discuss this”
9	69	12	“I didn’t know this was important, had I known I might not have stopped AS. I just felt helpless and I needed some control”
11	64	24	“I think we should have been offered some education on this stuff. I might have felt more positive if I had been”.
12	55	12	“any information on these things would have been good. I felt like an idiot when I mentioned these at my first appointment. The nurse was very dismissive”.